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ORIGINAL ARTICLE



Social insurance literacy: a scoping review on how to define and measure it

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ABSTRACT

Purpose: Sickness insurance and workers' compensation systems decide on peoples' eligibility for benefits, and are commonly based on medical certificates and assessments of work ability. Systems differ in the extent to which they preserve clients' dignity and right to fair assessments. In this article, we define a new concept for studying interactions between individuals and systems: *social insurance literacy*, which concerns how well people understand the different procedures and regulations in social insurance systems, and how well systems communicate with clients in order to help them understand the system.

Methods: The concept was defined through a scoping literature review of related concepts, a conceptual re-analysis in relation to the social insurance field, and a following workshop.

Results: Five related concepts were reviewed for definitions and operationalizations: health literacy, financial/economic literacy, legal capability/ability, social security literacy, and insurance literacy.

Conclusions: Social insurance literacy is defined as the extent to which individuals can obtain, understand and act on information in a social insurance system, related to the comprehensibility of the information provided by the system. This definition is rooted in theories from sociology, social medicine and public health. In the next step, a measure for the concept will be developed based on this review.

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► IMPLICATIONS FOR REHABILITATION

- Social insurance literacy is a new concept that is based on theories in sociology, social medicine and public health.
- It provides conceptual orientation for analyzing factors that may influence different outcomes of peoples' contacts with social insurance systems.
- The concept is of relevance for rehabilitation professionals since it focuses on how interactions between individuals and systems can influence the rehabilitation process.
- The study will in the next step develop a measure of social insurance literacy which will have practical applications for rehabilitation professionals.

Introduction

In sickness insurance and workers' compensation systems, access to benefits generally relies on various forms of eligibility assessments. These systems have different requirements and procedures for establishing the right to benefits, but a common aspect is that the claimant needs to provide documentation to support their claim, usually a medical certificate. Systems are often complex and require that the claimant can navigate through the different contacts that need to be taken, to acquire the needed documents, and to submit these to the insurer in a formally correct way. During an appeal process, the quality and correctness of the documents becomes even more important, as they are considered as part of the proof used in courts or tribunals. Several studies

have indicated how contact with such systems may be perceived as cumbersome or even have negative health effects [1–5], and that people with fewer resources risk being mistreated or offered worse service [6]. Previous studies have also indicated how eligibility assessments (e.g., work ability assessments) require adequate communication from professionals in the system in order for claimants to consider the assessment to have social validity, i.e., the extent to which it is considered acceptable or legitimate [7]. Hence, the actual outcomes and perceptions of a benefit claim may be influenced by the quality of medical certificates but also by the differences in resources among individual claimants, as well as the insurance organization's competence and skills in managing such differences.

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In a review of qualitative studies of interactions with workers' compensation systems, contacts were reported to be mostly negative, with considerable psychological consequences for injured workers, leading to the development of secondary injury rather than fostering recovery [8]. This pathogenic nature of interactions is related to the inability of systems to respond to needs among different claimant groups, and we see a cyclical pattern involving legitimacy concerns, adversarial relations, difficulties in getting diagnoses and treatment, chronicity of injuries and psychological consequences [8]. A similar lack of perceived legitimacy was found related to work ability assessments in the Swedish social insurance system [7], and related to contacts with system representatives [9]. The negative effects of compensation systems on claimants' health has been reported in different jurisdictions (e.g., [10]), and it has been concluded that systems that succeed in reducing adversarial interactions stand better chances of preserving the dignity of workers [2].

In a study of status meetings between the Swedish social insurance agency, employers, employees and medical professionals, it was noted how illness must be described according to a predefined vocabulary, using diagnostic classifications and being placed within the regulatory context, including the various time limits in the system [11], where the level of adherence to such language may influence the access to sickness benefits. Further, the client was the actor with least knowledge of regulations, but also the actor who had to deal with decisions made over their heads: "[f]ailure to engage competently in the discussion, often due to illness, meant decisions were made for them." [11, p. 1687].

Social insurance literacy

To establish a terminology for researching and discussing issues related to communication between clients and social insurance systems, we introduce a new concept: social insurance literacy. This concept aims to capture the importance of peoples' resources (economic, social or cultural), and the ability of systems to meet the varying needs of claimants, in relation to how the system performs. The concept is meant to be used to describe the various factors that may influence different outcomes of peoples' contacts with social insurance systems (e.g., access to benefits, or perceived justice), and to offer guidance in how these factors may be operationalized and measured.

The term social insurance is here used for various types of compensation systems related to work disability due to disease, illness or injury. In a European context this primarily refers to sickness insurance systems or work injury insurance systems; in a North American and Australian context it primarily refers to workers' compensation systems. In this article, we do not include welfare systems, unemployment insurance or social services in general, although the concept may have relevance also in this broader sense.

Aim

The aim of this article is to define the concept of social insurance literacy, and to provide orientation for how to measure it. This is done using a scoping literature review of related concepts and operationalizations, where these are conceptually re-analyzed in relation to the social insurance field. Specific research questions for the scoping review are:

- How are concepts related to social insurance literacy defined, and operationalized into measures?

- How may these definitions and operationalizations inform a definition and operationalization of social insurance literacy?

The article is organized as follows. First, a theoretical orientation for the development of the social insurance literacy concept is described. Thereafter, the methodology and procedure of the scoping literature review is presented, followed by the results of the review. In the discussion, the review results are conceptually re-analyzed and related to the social insurance literacy concept. The article concludes with a definition of the concept, and a direction for developing a measure.

Theoretical orientation for social insurance literacy

The notion of literacy related to social insurance rests on several theoretical assumptions, based on sociology, social medicine, and public health. The term "literacy" is, in this context, not primarily considered an individual asset or skill, but is related to a person's social position and resources in a specific setting. A key framework for social insurance literacy is the social determinants of health, which is an empirically driven research field that focuses on structural differences between groups in relation to their social status, and the consequences for their health development. The social determinants of health involve the conditions in which people are born, grow, work, live, and age, and the economic policies and systems, social norms, social policies and political systems that affect these conditions [12]. One useful concept in this field is the social gradient, that describes how the health within the population is closely related to income and education, where differences are not primarily found between the rich and the poor as distinct groups, but on a continuous scale where each step on the ladder provides better health [13]. Social stratification is a key notion in this framework, where the social gradient is related to power differences between groups in society. A policy conclusion from this research is the need for social investments, and for promoting proportionate universalism, i.e., these actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage [14].

A social medicine model developed by Diderichsen and Hallqvist [15] offers an understanding of the mechanisms involved in social stratification and health. According to Diderichsen and Hallqvist, an additional role of welfare systems is to even out or balance the structural forces of inequity. Social policy can directly target social selection through, for example, the educational system but it can also play an indirect role as a welfare system buffer. An important source of unequal health is exposure to detrimental work environments, which in turn can lead to absence from work. Sickness benefits schemes compensate for income losses and an anticipated negative spiral that, in the end, could start a downward social selection. The model discusses differential exposures, differential vulnerabilities and differential consequences as a result of the social gradient and differences in power and position. From this model, we can draw the assumption that differential social insurance management exists which involves a dynamic interplay between the client, the system and its officials. Social insurance literacy thus targets a specific part of the model in which the individual with health problems interacts with the social insurance system.

Drawing further on the interaction between the individual and the system, theories on agency is relevant as another perspective. Agency is a broad concept used in many disciplines. However, at the core is the relationship between two or more parties with more or less transparent agreements. In welfare systems there are agreements at the societal level that the clients in the system will

adhere to the existing rules and regulations. However, as rules are implemented into policy and practice, interpretation takes place and the street level bureaucrats have different approaches to this [16]. In relation to social insurance literacy we understand agency as the individual's will and capacity to act independently and, more theoretically, how the agent accommodates social practice in relation to his/her position in a certain field [17]. If the accommodation is supported by a transparent and well-functioning welfare system and institutional practices, then it would presumably strengthen the social insurance literacy, while the opposite would be anticipated in a complex and nontransparent system with repressive attitudes towards clients. It is noteworthy that an individual's general agency can be hampered not only by structural and institutional factors but also by the health problems experienced by the client.

Where research in public health has offered major contributions in providing empirical evidence for the relationship between social status and health, sociological theories have contributed with theoretical explanations for the mechanisms of social reproduction, to explain how social differences are created and upheld. The distribution of power within a community is based on peoples' position in the economic system, but also relate to status provided by a person's social position. A Weberian perspective on class and social position dictates that the outcomes of the social stratification of society are individual, but not the causes: a class is defined as a group of people that have in common causal components in their life chances [18]. In this view, social position is relative to others' social positions, which is in line with the research on social determinants of health, and the social gradient in life chances and health outcomes. Further, the works of Bourdieu [19] offer the perspective of structuralist constructivism to explain how such social structures are constantly created and recreated through the dynamics of social practices and power differences between individuals and groups. A key concept for Bourdieu is habitus, which is the mental and embodied structures through which individuals deal with the social world, which reflects the internalized social order and social position into which an individual has been socialized (e.g., through class, gender or other social categories). These structures are related to various combinations of economic, cultural, social and symbolic capital that define the social status (and thereby lifestyle preferences and career possibilities) of individuals [19]. Although many social characteristics of individuals are structurally determined by the social position given by birth, the habitus concept also emphasizes that life courses are not fixed, and that the habitus of an individual will evolve as the person is exposed to and become a member of different social contexts.

The combination of theoretical approaches from sociology, social medicine and public health hence provides orientation for our further conceptualization of social insurance literacy, as these serve to explain social dynamics related to how individuals interact with and within systems, and how this may differ across a population.

Methods

The review was conducted using a scoping methodology, which aims to summarize research in a specific field or pertaining to a specific research topic and make a critical examination and re-interpretation of the research. A suggested model for scoping reviews comprises five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing and reporting the

results [20]. An optional sixth step, consultation with practitioners or consumers, is also proposed, which we included in the form of a workshop and a conference discussion. In the review, as suggested by Arksey & O'Malley, a descriptive-analytical approach was applied, where the research identified as relevant was described and re-analyzed in relation to the developing concept of social insurance literacy. This also involved a mapping of the identified concepts, where the purpose was "to establish how a particular term is used in what literature, by whom and for what purpose" [21, p. 8].

Identifying the research question

Because no literature exists on social insurance literacy, we focused the review on related concepts. We defined a related concept as a concept describing similar issues, i.e., relating to the various capacities among a population to understand and use information to specific ends. Specifically, we searched for studies that related these issues in relation to social security, welfare systems or insurance systems. Because the literature reviewed did not explicitly deal with social insurance literacy, the approach toward inclusion was not as strict as in regular scoping reviews, but was related to whether or not a comparable concept was identified, and whether or not the context of the study could be considered having relevance for or be transferrable to a social insurance context.

Identifying relevant studies

A combination of database searches (for peer-reviewed literature), Google searches (for gray literature) and hand searches were carried out. Database searches were conducted in Scopus and UniSearch in March 2018. The choice of databases was made based on breadth and comprehensiveness, where the chosen ones cover several other databases. Scopus is primarily a social science database but covers several research fields, including science, mathematics, engineering, technology, health and medicine, social sciences, and arts and humanities; it also offers full PubMed coverage. UniSearch is a database search tool provided by the Linköping University library, covering a wide range of databases and local library catalogs; the tool is provided by EBSCO and is a discovery service which regularly collects metadata from a number of databases. Search terms for these searches are described in Table 1. Google searches were carried out with different combinations of the search terms. Hand searches were carried out based on references in identified papers, and papers identified through contacts with experts in the field.

Study selection and charting the data

The search results were scanned for relevance in the first step, i.e., searching for relevant titles and abstracts, and performing word searches within search results to identify in which contexts the search terms were used. This process facilitated the management of the search strings that yielded a large number of references, but can imply that some relevant papers were missed. Reference lists in relevant papers were used to find additional studies of relevance. The final selection included 83 papers and reports, of which 46 on health literacy, 13 on financial/economic literacy, 11 on health insurance literacy, 8 on legal capability/literacy/empowerment, and 5 on social security literacy. These 83 papers and reports were read in full and summarized in an Excel file, including information about jurisdiction, if they were peer-

Table 1. Search terms used in the literature review.

Purpose	Search terms	References
Identifying concepts and relevant studies	literacy OR capability AND "social insurance" OR "social security" OR "workers' compensation" OR "welfare system" OR "sickness insurance"	Scopus: 346 UniSearch: 3493
Identifying studies in a relevant context	"health literacy" OR "legal capability" OR "social insurance literacy" OR "social security literacy" OR "financial literacy" OR "economic literacy" OR "insurance literacy" OR "legal literacy" AND "social insurance" OR "social security" OR "workers' compensation" OR "welfare system" OR "sickness insurance"	Scopus: 36 UniSearch: 655
Definitions and measures	"health literacy" OR "legal capability" OR "social insurance literacy" OR "social security literacy" OR "financial literacy" OR "economic literacy" OR "insurance literacy" OR "legal literacy" AND definition OR measure*	Scopus: 2623 UniSearch: 15871

reviewed or not, aims and scope, central concepts and their definitions and measures, methodology, results/conclusions, and relevance for the present study (see [Supplementary Table S1](#) for an overview of the included studies).

Collating, summarizing, and reporting the results

Following the review, a first draft of the results was written by the first author and discussed at a workshop, where the structure of the report was based on the different identified concepts with regard to definitions and operationalizations. The purpose of this was to scrutinize the preliminary review results and to reanalyze the material. The workshop may be considered as a variant of the sixth step proposed by Arksey & O'Malley [20], where we aimed to use a group of content experts to discuss the results of the review, and to produce a definition of social insurance literacy and initiate the development of a measure. The workshop was carried out over 2 days in June 2018 with 11 participants from Sweden, Canada, the Netherlands and Australia, with expertise in sociology, social medicine, law, rehabilitation, social insurance, epidemiology, occupational therapy, and public health.

At the workshop, the review was used as a starting point for defining social insurance literacy, and the discussion indicated the complex nature of the concept. The workshop resulted in a tentative definition and a matrix describing its different domains. The results of the workshop were then summarized and sent out for comments, which resulted in a revised definition. This was revised further after a seminar arranged at a pre-conference to the European Public Health conference in Ljubljana in November 2018, arranged by the section for Social Security, Work and Health, into the final definition presented in this article.

Review results

In this section, we present a review of the literature on the related concepts identified in the literature search. Because the aim of the review is to have a foundation for defining and measuring social insurance literacy, the review targeted the definitions and scope of the central concepts in the included studies, and how these concepts are operationalized into measures. The outcomes of the included studies were given less priority. Studies not using a specific concept were included if they had topical relevance which could inform the development of the social insurance literacy concept. These results are discussed in relation to their relevance for the focus of the present study in the next section.

Definitions and scope of reviewed concepts

There is considerable variation in how related concepts are defined, and the same concept may be defined in different ways

in different studies. Some concepts are broad in their scope and may be applied to multiple settings (such as financial literacy, applicable to all areas where an understanding of economics is needed), while some had a more limited scope (such as social security literacy, which exclusively focused on understanding of regulations related to specific benefits). The reviewed concepts are here presented based on order of literature size.

Health literacy

Health literacy is by far the most researched concept among those reviewed. Not only has the concept been used and researched in abundance – the research has grown exponentially, with more than 6000 research papers in 2016 [22]. There has also been much activity over the last decade in reviewing existing definitions, conceptualizations and measurements – in our nonexhaustive review, more than two dozen papers explicitly aimed to provide such reviews or offer accounts of the historical development of the concept. Recurring conclusions from these papers are that there is no consensus or gold standard either in defining or measuring health literacy, and that the development has gone from simple individual-oriented screening tools toward more comprehensive and multidimensional constructs [23].

Development and distinctions: In a chapter describing the development of the health insurance literacy concept and the related research, Rudd [24] notes how it was born from an observation that literacy had an association to health outcomes, which spurred an interest in the relationship between individual resources and health. One of the most influential definitions and distinction of different aspects of health literacy was proposed in 2000 by Nutbeam. He defined health literacy as "personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health" [25, p. 264], and made a distinction between various forms of literacy, namely functional, interactive and critical. Functional or basic literacy refers to basic skills in reading and writing; interactive or communicative literacy refers to more advanced cognitive and social skills oriented towards participating in various forms of communication and applying information to changing circumstances; critical literacy, finally, refers to a yet more advanced level of literacy involving critical analysis of information and the capacity to use this information to exert greater control over life events and situations [25]. Although these distinctions provide nuance to the concept, it does focus on individual skills and capacities, and how these can be applied in different situations. Because the first definitions were much oriented towards individual skills and knowledge, Rudd describes how this led to a number of measures that disregard the "difficulty of tasks as well as texts, the communication skills of those charged with presenting health information, or the context within which dialogues and interactions were taking place" [24, p.

64]. The focus of more recent studies (and definitions) are more concerned with the contextual and social aspects of health literacy.

Different perspectives and uses

Several authors, including Nutbeam [26] and Pleasant [27], note that health literacy has been developed and conceptualized through two perspectives: as a risk factor (i.e., a preexisting factor to take into account in clinical settings), or as an asset (that it is possible to influence through health education and other interventions). While both has their relevance, the latter perspective points to the importance of social determinants of health, and to the importance of considering health literacy as not merely an individual trait, but as a result of socio-economic and other social factors. The distinction between functional, interactional and critical health literacy is related to these perspectives, where it has been noted how measures of the latter two variants need to include social factors, such as negotiation and advocacy skills [26]. The risk/asset perspectives of health literacy have in several studies been connected to different disciplines, where the former is associated with a medical perspective, developed as a clinical screening tool, and the latter to an adult education or public health perspective, developed as a health promotion concept [27–29]. Critical health literacy has also been discussed more in the public health-oriented literature, which tends to emphasize the social aspects of the concept. This focus has even spurred the development of a “public health literacy” concept, defined as “the degree to which individuals and groups can obtain, process, understand, evaluate, and act on information needed to make public health decisions that benefit the community” [30, p. 446], and where the concept primarily seem to comprise knowledge and skills in public health concepts and information.

Criticism: The concept and its uses have also been criticized, e.g., for not being distinctive from the broader term cognitive ability [31]. However, that study conceptualized health literacy as an individual skill set, which makes the critique less relevant if it is seen from a social perspective. Another critique focuses on the increasing number of domain-specific and detailed definitions and assessments, where it is argued that a more general definition of health literacy would be more helpful to combat fragmentation, to emphasize the similarities between the various studies focusing on different contexts and groups, and to improve generalizability and comparability [32,33]. Pleasant [27] argues that health literacy is a complex social construct, and as such, the definition is of key importance for developing a relevant measure, since it will influence what we study and how it is used. Measuring health literacy as an objective or naturally occurring phenomenon is hence, Pleasant argues, misguided [27]. It has also been observed that most definitions and measures of health literacy tend to focus on understanding of written materials, while much communication may be in other forms – oral health literacy may, for example, be different from other forms of literacy [23,26,34].

Antecedents and consequences: Another review of health literacy definitions and models [35] focused specifically on health literacy among children and youths, but the thorough analysis has relevance also for other applications. An interesting feature of the study was an analysis of antecedents and consequences of health literacy in the models reviewed. Twelve of the models included antecedents, which were individual characteristics, demographic, situational or contextual factors, and broader system or social factors. The system or social factors seemed to be most commonly evaluated through navigation skills, and skills related to civic

issues. Fifteen studies included consequences related to improvements of health literacy, which were mostly related to health behavior and empowerment, but also potential benefits for individuals, communities and societies. The study also points out that, although definitions tend to include contextual factors, measures still tend to focus on individual factors and skills. A risk with this, it is noted, is that it may lead to an understanding of health literacy as an individual responsibility, which may lead to an individualization of structural and social issues, and overlook the social determinants of health. The study concludes that health literacy studies need to situate research in context and observe the social practices in which it is performed, which is however a more challenging construct compared to individual-oriented surveys.

Financial literacy

Financial literacy is a relatively established term used to study individuals’ skills and capacities to understand financial issues and to make reasonable market choices. Definitions are generally oriented towards financial literacy as an individual asset. The reviewed literature was dominated by studies in a US context; one possible explanation for this, one study argues, is that financial literacy is given less importance in countries with more generous social security systems, since these give people fewer incentives to save and accumulate wealth and hence to invest in financial literacy [36]. However, a review of the evidence seems to assess US citizens’ financial literacy as lower compared to their European counterparts [37].

One review [38] analyzed a large number of peer-reviewed empirical studies and proposed a definition (“how well an individual can understand and use personal finance-related information”, p. 306) and a way of measuring it by differentiating between a knowledge and an application dimension – in order to be financially literate, one needs not only to have knowledge, but also to be able to use the knowledge in an appropriate way. Hence, an instrument needs to include items to measure both of these dimensions. The study also emphasizes that such a measure would be limited to the human capital in relation to financial situations, which may be used to predict behavior and outcomes, but will not ensure that “appropriate financial behavior” will occur, since behavior may be influenced by external factors, biases, or impulsiveness.

A more elaborated conceptualization of financial literacy is found in a study [39] which is critical to the previous literature, and argues that the bulk of financial literacy research defines it as an autonomous skill-oriented capacity of individuals, and that low levels of literacy according to this perspective may be remedied through educational interventions in order to facilitate peoples’ possibilities of making appropriate financial decisions. The paper questions this line of argument and makes a point for considering financial literacy (and any other literacy) as a situational concept, defined through the social context in which it is practised. This study illustrates some of the normative bias that is inherent in financial literacy studies and places this research field into the overall context of financialization of society, where knowledge of specific financial systems is defined as important.

Health insurance literacy

Health insurance literacy is a concept used almost exclusively in a US context, where the most common objective of the studies is to study differences in the population regarding market-choices related to private health insurance. Definitions of the concept are

corresponding to this focus, e.g. “consumers’ ability to select and use private health insurance” [40, p. 225] or “knowledge, ability, and confidence to effectively choose and use health insurance” [41, p. 10]. Some of these studies almost exclusively focus on individual resources, capacities and demographic conditions [40], while some also include an element of interaction with insurance systems. One study presents a conceptual model [42], where health insurance literacy is composed of financial literacy, numeracy, demographics, health literacy (individually oriented), and patient-provider communication, where the concept is operationalized into knowledge of terminology and proficiency in using the Medicare system. This study concerns understanding of the system in a more general sense compared to the social security literacy measures, which were very detailed about specific regulations. One study [43] investigated the same topic in another jurisdiction (Israel). The context differed from the US studies since it was conducted in a system with general health insurance coverage, where the study focused on knowledge and use of supplementary private insurance.

Legal capability

Legal capability (or, in some studies, legal literacy or legal empowerment) is a relatively new concept that does not seem to have generated many peer-reviewed papers. A few reports summarize existing research on the concept, which generally seem to have been little focused on developing the concept or valid measurements of it. One exception is a report [44] which includes a conceptual analysis comparing definitions and how these are broken down into sub-domains. In this report, legal capability/literacy is defined as “abilities that a person needs to deal effectively with law-related issues ... beyond knowledge of the law, to encompass skills like the ability to communicate plus attitudes like confidence and determination” [44, p. 15]. The study makes comparisons with health literacy and suggests measurements including tests of peoples’ capacities to interpret legal texts. It emphasizes the importance of general literacy and social determinants to explain vulnerable groups’ societal barriers. Most studies in this field do, however, seem underdeveloped, or insufficiently research-focused. It could further be noted that the term may be used differently, e.g., in disability and human rights settings. We have chosen to use the terms identified in the studies, although “legal literacy” could perhaps be a more adequate term.

Social security literacy

Social security literacy is a concept used only in studies conducted in the US, where the few available studies are generally published in non-peer-reviewed reports [45]; only one study [46] was published in a peer-reviewed journal. The concept is not explicitly defined in the studies but is generally described in relation to financial literacy. In operationalizations of the concept, it is related to individuals’ knowledge of specific system regulations, and measures are generally quiz-like. The studies explore differences in knowledge across population groups. The measures of social security literacy are hence of a rather technical character and focus almost exclusively on individuals’ level of knowledge about how the system works, although some questions focus on trust in and expectations on systems.

Operationalizations and measures

In this section, we shift our focus from the conceptual level to how the definitions reviewed above have been operationalized into measures.

Health literacy is, since it is the most established concept, also the one which has resulted in the largest number of measures. One review [47] has counted more than 150 measures and concludes that still no “gold standard” has emerged. Most measures are primarily focused on measuring health literacy on an individual level. The review also identifies a lack of relationship between the definitions of health literacy and how it has been operationalized into measures. There are a number of measures developed in the earlier years of the research field, which all have in common that they focus on individual skills and capabilities, mostly limited to what Nutbeam [25] defines as functional literacy. Examples of such measures are Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA).

One of the most comprehensive measures of health literacy is the European Health Literacy Questionnaire (HLS-EU), which contains 47 items related to three domains: healthcare, disease prevention and health promotion; it includes individuals’ subjective assessment of their capabilities to access, understand, appraise and apply health information [48]. The measure is also available in two shorter formats, consisting of 16 and 6 items, respectively, developed through Rasch modeling [48]. The HLS-EU can be considered to cover functional, interactive and critical health literacy, but is limited to an individual and a subjective (i.e., self-reported) perspective. Other measures that cover similar aspects are the Japanese functional, interactive and critical health literacy scales, which have also been translated to a Swedish context [49,50]. The use of subjective versus objective measures has been discussed by Nguyen et al [47], where both have advantages and drawbacks: subjective measures are generally easier to carry out, with less cognitive effort compared to objective tests of individual capabilities; a limitation is the lack of information about whether the reported skills are related to actual skills.

Rudd has called for measures that are not limited to individuals’ capabilities or perceptions, but that also includes professionals’ communication skills, and which consider institutional and system-related norms, policies and regulations [24]. Because health literacy is a situational and interactive concept, individual measures are limited and lead to misinterpretations. Measures therefore need to include multiple literacy skills, and an analysis of the tasks that people are expected to do, in terms of their complexity [24]. There are a few examples of methods that assess healthcare contexts, e.g., the spatial environment in hospitals in terms of accessibility [51]. Such methods are interesting because of their explicit focus on context and how it will influence peoples’ ability to access and communicate with the healthcare system.

The available measures of financial literacy, health insurance literacy, legal capability and social security literacy, are generally focused solely on individual skills, commonly related to knowledge of details in specific systems, or related to competencies in making informed market choices. A few questions from these studies are related to contextual issues, for example, how knowledge of financial issues is applied in practical situations [38], or relate to individuals’ perceptions, experiences and/or expectations of systems, e.g., questions about the expected level of benefits [45], or tests of how well respondents can interpret legal texts [44]. Although these studies do not generally contribute with specific formulations that are applicable to other contexts, they may

serve as inspiration for the kind of questions that may be relevant to assess respondents' knowledge of system-related issues or their capability of interpreting system-related information.

Discussion

Our scoping review identified literacy concepts in relation to health, health insurance, social security, financial issues, and legal capability, with different conceptual and theoretical underpinnings. While some barely have any explicit theoretical assumptions (e.g., social security and health insurance literacy), some are clearly based on theory development and empirical research (e.g., health literacy). The concepts also represent different scientific disciplines, e.g., economics (financial, health insurance and social security literacy), law (legal capability), medicine and public health (health literacy). Health literacy is the most established concept, and has evolved to increasingly focus on social and situational conceptualizations, while a focus on individual characteristics is dominant for most other concepts. Studies on social security literacy and health insurance literacy are almost exclusively carried out in the US, while the other concepts have a more international distribution. A large number of measurements exist, especially for health literacy, and the individual perspective dominates the measurements, most commonly though subjective self-assessments. Measurements assessing objective literacy (e.g., through tests or assessments) are uncommon.

None of the reviewed concepts focuses on the specific characteristics relevant for analyzing the interactions between individuals and social insurance systems, and the potential consequences of such interactions, e.g., in terms of access to benefits or perceived justice such interactions. On the basis of these results, we conclude that the establishment of social insurance literacy as a new concept is warranted since it outlines different factors compared to the existing related concepts.

Defining social insurance literacy

A definition of social insurance literacy needs to consider the relationship between individual and system-related factors. It also needs to capture the dynamic nature of social insurance literacy and how it changes, both relating to how individuals learn to handle the system, and to how systems change with regard to regulations and how they communicate with clients.

From the review, we find that health literacy is the most relevant of the concepts when developing a definition of social insurance literacy. We especially consider the literature from public health sciences to be relevant as it has a strong theoretical foundation which corresponds well to the framework presented in this study. Further, the distinction between functional, interactive and critical health literacy [25] is useful for conceptualizing the individual level of cognitive, social and other capacities, which is likely to be transferable to a social insurance context. One criticism of health literacy has been the increasingly detailed conceptualization of similar phenomena into specific contexts [31], where it could be argued, along these lines, that social insurance literacy is merely another domain in which general literacy matters. As a response, as Rudd [24] argues, literacy understood as cognitive ability is not the same phenomenon as health literacy, and hence not as social insurance literacy. Along the same lines, social insurance literacy is not simply health literacy in another context, since there are, apart from the similarities, likely other factors influencing the literacy related to social insurance than to health.

We may expect social insurance literacy to have many similarities to health literacy, e.g., focusing on peoples' interactions with social systems, their abilities to understand and act on information related to these systems, and to depend on an interaction between a person's social position and resources and the system's ability to communicate and act in a comprehensible way. It is also likely that the theoretical foundation for health literacy is largely transferable to social insurance literacy. These similarities will likely imply that there will be some overlaps in how the concepts are defined. We will likely want to include an individual aspect related to a person's possibilities to obtain, understand and act on information, and we will need to take the system side into account and how such information is communicated.

The differences between the concepts and how they are defined will be based on the specific conditions that will influence the communication, and the various processes involved in which people interact with the system. Social insurance is a type of system in which economic compensation is provided to those who have been determined to be work disabled due to sickness or injury, which means that the systems will often be administered through bureaucratic public authorities. This implies that the type of communication is likely to be heavily regulated and formalized, and that specific procedures will be expected, e.g., to determine eligibility for benefits. Communication with the system will also refer to different phases of a claims process, from an initial application to a final decision, where the time in between can be long depending on the type of sickness or injury or other reasons, e.g., bureaucratic delays [52]. Hence, there are several differences from the context of health literacy, which is usually within a healthcare setting. Social insurance literacy as a concept may also have relevance for more than one context, since the healthcare system and the person's workplace are involved in a rehabilitation process; at this stage, however, we will focus the concept on interactions with the insurance system, but where actions from other actors may also be relevant, e.g., by providing certificates to the system.

One of the most referenced definitions of health literacy is Nutbeam's, where it is presented as "personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health" [25, p. 264]. This definition is an early one, and lacks the social context and the importance of how well information is presented by system representatives. We can however use this definition as a starting point for the individual side of the concept.

An excessive focus on individual skills risks placing the concept into an individualistic empowerment-oriented framework, which is not our purpose. The aim is to use the concept to analyze relationships between structural and contextual issues (e.g., related to providers' communication, system designs and regulations) and individual characteristics (e.g., related to cognitive abilities or social gradients in resources). This multi-dimensional concept will facilitate analyses and reforms of systems to better suit the various needs of different groups.

A common objection towards health literacy studies is that they do not sufficiently focus on the system side of the information exchange, and it is still uncommon to see empirical studies that measure or in other ways assess this. We may hypothesize that there is limited literacy within the system as such, e.g., due to limited communication skills among professionals (not being able to present the system comprehensibly or offer adequate help to clients), or to organizational constraints, which will influence the communication. For social insurance literacy, this may

concern requirements in relation to how letters and decisions are worded, procedures for eligibility assessments, or organizational factors such as heavy caseloads.

Given these considerations, we propose the following definition that includes both individual capabilities and the system's ability to communicate in a comprehensible way:

Social insurance literacy is the extent to which individuals can obtain, understand and act on information in a social insurance system, related to the comprehensibility of the information provided by the system.

Developing a measure of social insurance literacy

As for developing measures, the less theoretically oriented studies, e.g., on health insurance literacy, may be of conceptual interest for the present study, e.g., regarding the choice of determinants. However, the determinants used in these studies did not differ significantly from those identified in the more comprehensive and theoretically informed health literacy studies. In developing social insurance literacy, we may assume that the antecedents will be dependent on individual factors such as socio-economic status or education, and on system-side factors such as how system representatives communicate. Consequences of high or low literacy in this area can refer to the likelihood for a person to be assessed as eligible for benefits, or to perceived justice in their contacts with the system. These determinants and outcomes of social insurance literacy need to be measured through specific survey questions or register data that will be outside the measure of literacy, e.g., through demographical variables, and by combining a literacy measure with other questions of interest, e.g., measures of perceived justice.

Social insurance literacy may be measured in different ways. The individual aspects can be assessed through subjective or objective measures – e.g., through asking about how well people understand system information, or through testing them by including tasks of interpreting system communications. Assessing the system's literacy can be done indirectly through questions to people who have had contact with the system about how they perceive that the social insurance system communicates with them. It could be assessed more directly by (subjectively) asking system representatives about the content of their communication and their communication strategies, or (more objectively) by observing communication practices.

Any measure needs to balance feasibility and comprehensiveness. A measure that includes both subjective and objective aspects and that considers both the system's and the individual's perspective will likely be difficult to manage in practical research, and will be prone to many contextual variations which will make comparative studies difficult. We therefore advocate, as a first step, to develop a simple measure which focuses on individuals with experience of contact with the system, with a focus on subjective questions about how the interaction is perceived. Given that people act based on their understandings, it is fruitful to understand these perceptions [53]. The problem with including objective measures is that these will need to rely on system-specific information that the respondents will interpret, which will differ across jurisdictions, and which may change over time.

Objective and system-side measures may be developed in a later stage and the results of such measures can then be related to the subjective measures outlined here. Qualitative studies could add in-depth information on communication practices, and may be more relevant for assessing system-side communication than quantitative measures. Likewise, qualitative studies may be helpful for analyzing how individuals interact with and learn from

interactions with systems, and how they are supported through their social networks, such as family, friends or other professionals.

In an ongoing study, we are developing the social insurance literacy questionnaire (SILQ), which is to be tested and validated in a Swedish social insurance context. The measure will be based on the definition and considerations made in this article, and the results will be presented in a subsequent paper.

Conclusions

To facilitate theoretically informed research on interactions between individuals and social insurance systems, and how this relates to the social resources of individuals and the communication strategies by systems, we have developed a new concept: social insurance literacy. We define it as the extent to which individuals can obtain, understand and act on information in a social insurance system, related to the comprehensibility of the information provided by the system.

This definition is based on a review of existing literature on related concepts, an international workshop and a conference seminar, where the results from the review was discussed and the concept was developed.

The social insurance literacy concept may be used to foster new research that combines theoretical insights from sociology, social medicine and public health. We also describe some outlines for developing a measure based on the definition, where such a measure will need to balance practical feasibility and comprehensiveness.

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